

# Developmental Disabilities Council

## Reading Cover Page

Date: September 16, 2004

Meeting: Public Policy Committee

**Reading Number: 04-P8**

**Issue: Discussion on Choice**

### Included in this Reading:

- Discussion Paper on Choice
- Council Policy No. 11- Supporting Families Facing Developmental Disabilities Issues
- Council Policy No. 114 – Self-Determination and System Reform

### Background/Summary:

The committee requested a further discussion of the concept of “choice” and what it means, particularly in relation to DD residential services.

Action:  
Discussion

If there are any questions, please contact  
Donna Patrick at 1-800-634-4473 or  
[donnap@cted.wa.gov](mailto:donnap@cted.wa.gov)

DISCUSSION PAPER ON CHOICE  
DD Council Public Policy Committee  
September 16, 2004

Values Statement:

Choice is an important value in the DD system. We work toward people having as much choice in services and everyday life as possible. We value individuals with developmental disabilities achieving independence, productivity, inclusion and integration in their communities.

Issues Statement:

What does choice really mean in the context of DD services in Washington State? In relation to residential services, do parents and guardians of adults who have developmental disabilities have the right to insist that their residential services be provided in the institution of their choice? What are the rights to choice for people who want residential services in the community

or are not receiving any services at all because of insufficient funding?

## Background on Residential Services:

Most of DD services in the state of Washington are funded jointly by the state and federal government under the Medicaid program. Residential services are provided at a DD institution through the Intermediate Care Facilities for the Mentally Retarded or ICF/MR program or in the community through a Home and Community Based Waiver.

Under the ICF/MR program, federal law requires that individuals eligible for an ICF/MR (more commonly called a DD institution, a Residential Habilitation Center or an RHC) are entitled to that placement.

Medicaid also allows states to create a Home and Community Based (HCB) Waiver, also called the Community Alternatives Program (or CAP) waiver as an

alternative to institutions. DDD previously had one CAP waiver program. That has been replaced by four new waivers for different levels and types of service (Basic, Basic Plus, Core and Community Protection). A person on one of these waivers is entitled to the amount and level of services authorized under that waiver. Theoretically, the person with developmental disabilities who qualifies for services in their individual assessment and plan is required to receive those services. However, the Division is not funded to provide all qualified people with services and is directed by the federal government to create waiting lists for people they cannot serve on the waivers. Not everyone who is eligible for DD services is on a waiver.

For both institutional and waiver programs, individuals are allowed to choose their provider if that provider has the ability to meet the person's needs. The person doesn't always get to receive that choice because the RHC or community provider

may not have the capacity to serve them. In other words, **the state has an obligation to provide an array of choices, but does not have the obligation to provide every individual's choice.** An example is Frances Haddon Morgan Center (FHM), one of the state's five DD institutions. FHM is typically filled to capacity (53 clients). Government does not have to fund additional beds at FHM because parents choose or want to put their child there. Nor does a community provider have to expand its program to accommodate every person who desires that particular provider. In the Fircrest litigation, the King County Superior Court ruled..."It is the role of the legislature, not the court to set policy and decide how tax dollars are to be spent."

**The right some people have under federal law is to a level of services, not a specific location for those services.** The Court also ruled that..."the plaintiffs have not cited to any authority in both state and federal law that confers a right upon a

resident of an RHC to reside in a particular institution.” The State Supreme Court Commissioner in June denied the request for discretionary review by the State Supreme Court, thus upholding the Superior Court ruling that continues the downsizing of Fircrest.

People moving from Fircrest will continue to receive \$150,000/year services at another institution if they choose. Money will follow them into the community to provide appropriate services there if they choose that option

Basic philosophical questions about choice:

- What does “choice” mean?
- Does choice mean what an individual wants or what an individual needs?
- Who determines a person’s choice – the person with a developmental disability or the parent/guardian?

- Does choice mean choosing between two or more options or between a single option and nothing? (For example, a choice between an available community option and an available RHC option or between an RHC and nothing)
- What choices do the 9,000 individuals and families waiting for services have?
- What is the role and responsibility of government in providing individuals with developmental disabilities with their choice of services?
- When is the government responsible for meeting a person's needs and wants?
- Who should pay for our choices? Who should get what at the expense of whom?
- Are we all limited in our choices by resources?
- Does going to a public system (like DDD) for services automatically subject you to the limits of that system's funding and policies?





## Policy No. 111

# **Supporting Families Facing Developmental Disabilities Issues**

Adopted: January 21, 2000

The Developmental Disabilities Council believes in supporting families.

Families are whoever they determine themselves to be; this may include people beyond the biological family and/or household.

Resources should be available to support the needs of families.

Supporting families requires a mindset of building on people's strengths and capacities in a holistic, ethnically and culturally sensitive manner.

Supporting families requires an environment in which individuals with developmental disabilities and their families work together to:

- Determine their own goals;
- Experience their own power;
- Exercise choice;
- Develop positive relationships with people in their communities; and
- Be supported in their communities to care for each other.

Supporting families means:

- Reflecting the importance of prevention or intervention at the earliest possible opportunity;
- Responding flexibly to the needs of families and individuals; and
- Supporting opportunities for families to become better connected to each other and their communities.

The Developmental Disabilities Council believes that communities, together with public and private entities, can support an individual- and family-centered/directed system that:

Exemplifies and promotes an ethic of prevention and early intervention to ensure that supports for families are early, proactive and address needs before crises develop;

Designs policies that provide families and individuals access to supports and services early enough to minimize or prevent crises, financial impoverishment or relinquishment of parental rights and responsibilities;

Provides a forum for a collaborative, planning process with families that respects families' values and is ongoing and multidisciplinary;

Provides incentives to organizations, agencies and groups to empower and support families and individuals;

Ensures accessible, dependable, quality, statewide services and supports are available for families;

Ensures outcomes are based on quality-of-life indicators;

Supports families and individuals who chose to care for family members or themselves in their own homes and communities;

Provides options that enhance the safety and well-being of all family members;

Provides support and services in an efficient and effective manner.

Is evaluated by people receiving services to determine the degree to which these principles are implemented.

Ed Holen, Executive Director  
1-800-634-4473 or (360) 586-3560  
[edh@cted.wa.gov](mailto:edh@cted.wa.gov)



## Policy No. 114

### **Self-Determination and System Reform**

Adopted: July 16, 1999

The Developmental Disability Council supports self-determination for all people with developmental disabilities.

Self-determination includes, but is not limited to, a personal centered focus, real and comparable choices, control over financial and other resources, ways to determine satisfaction, access to the local community, and self-advocacy.

A person's services and supports must ultimately promote independence, productivity, integration and inclusion into the local community and reflect principles of self-determination.

Therefore, system reform proposals must also reflect principles of self-determination.

To the Developmental Disabilities Council this means that system reform proposals must:

**Be Person Centered:**

Proposals must place the individual with a developmental disability at the center and include planning mechanisms that focus on the person.

If the family is involved, e.g. the person with a developmental disability is under age 18, the proposal must respect and support the family and acknowledge the unique strengths/needs of the family.

Proposals must assure that the person with the developmental disability is in the decision-making role to the maximum extent possible.

**Include Real and Comparable Choices:**

Proposals must set out real choices and service options that assist the person in meeting his/her own individual plan. Proposals must assure that decisions about the choices are made with the full knowledge of the decision-maker.

Proposals shall include protections for individuals and a description of how they can exercise those protections.

Proposals shall include a means to enhance informed decision making to those considering the service or support.

#### Place Individual in Control of Recourses:

Proposals must include user friendly ways to place control over resources, including financial, in the hand of the individual decision-maker.

Proposals must include necessary safeguards to help the person determine how well the purchased service or support is helping the individual reach the goals of his/her own person-centered plan.

## Ways to Determine Satisfaction:

Proposals must include mechanisms to determine individual satisfaction and feed this information back to providers and system administrators.

Proposals must include tools for people to change services and/or providers when he/she is dissatisfied.

Proposals must outline individual protections and how the person can exercise those protections.

## Community Involvement:

Proposals shall address how individuals with developmental disabilities access community services, including but not limited to, housing, transportation, public facilities, and public services.

Proposals shall address how individuals with developmental disabilities are active in their local communities and how communities can engage in strategies to become more inclusive and integrated.



## Be Culturally Competent:

Proposals shall assure that services and supports are provided in a language understandable to the individual with a developmental disability and are culturally relevant in terms of commitment, availability, accessibility and appropriateness.

## Provide Transitions:

Proposals must recognize the life-long nature of the disability and accommodate easy movement when a person reaches change-moments during the life span.

## Include Sound Management Practices:

If system reform proposals are adopting “managed care principles” or modification thereof, they must address how they are going to be fairly and equitably applied in such areas as:

- Individual Resource Management/Community Guides

- Education Awareness and Information Sharing
- Personal Assistance Services
- Outreach and Prevention Strategies
- Eligibility and Service-level Determination
- Rate Determination
- Safety Net
- Special Needs and Those Facing Challenging Situations

Ed Holen, Executive Director  
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[edh@cted.wa.gov](mailto:edh@cted.wa.gov)